

## EXTENDED REPORT

## Prevalence and predictors of disability in valued life activities among individuals with rheumatoid arthritis

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**Objective:** To identify the prevalence of disability in a wide range of life activities and identify factors associated with such disability using the Verbrugge and Jette disablement model as a framework.

**Methods:** Data were from a panel study of 548 individuals with rheumatoid arthritis, interviewed annually by telephone. Valued life activity (VLA) disability was assessed using a 26-item scale rating difficulty in carrying out each activity. Three types of summary measure were calculated: activities unable to perform, activities affected, and mean difficulty. Subscale scores were also calculated, corresponding to obligatory, committed, and discretionary activities, as defined in the disablement model. Disease status measures were examined as predictors of VLA disability using multiple regression analyses.

**Results:** Half the subjects were unable to do at least one VLA. Approximately 2%, 31.3%, and 40.2% were unable to do at least one obligatory, committed, and discretionary activity, respectively. Almost all (95%) reported at least one VLA affected by rheumatoid arthritis; 68.4%, 91.4%, and 92.5% reported at least one obligatory, committed, and discretionary activity, respectively, affected. Disease status measures were robust predictors of VLA disability, accounting for 22–47% of the variation in VLA disability (with one exception). Adding the health assessment questionnaire (HAQ) to these models increased ( $p < 0.0001$ ) all model  $R^2$  values. HAQ score mediated the effects of many disease measures, consistent with the disablement model.

**Conclusion:** VLA disability was common, with more disability noted in committed and discretionary than obligatory activities. Because VLA disability has been linked to psychological wellbeing in previous studies, identification of factors that may protect against such disability is important.

Two models have driven the bulk of disability research. The first is that of the World Health Organisation (WHO).<sup>1–4</sup> Although useful in some situations, substantive problems have been reported in attempts to use the WHO model to guide research.<sup>5</sup> The second model was developed by Nagi, later amended by the Institute of Medicine, and then expanded by Verbrugge and Jette in their model of the “disablement process.”<sup>6–7</sup> This model encompasses four components:

- **Pathology:** Biochemical and physiological abnormalities, or disease, injury, or congenital/developmental conditions.
- **Impairments:** Dysfunctions or significant abnormalities in specific body systems that can have consequences for physical, mental, or social functioning.
- **Functional limitations:** Restrictions in performing generic, fundamental physical, and mental actions used in daily life in many circumstances.
- **Disability:** Difficulty performing activities of daily life.

The disablement process was described as a pathway progressing from pathology, to impairments, to functional limitations, to disability. Verbrugge and Jette also recognised that certain predisposing factors, termed “risk factors,” could affect the presence or severity of impairments, functional limitations, or disability.

When assessing disability, Verbrugge proposed that life activities be grouped into three categories<sup>3–7,8</sup>: (1) *obligatory* activities, required for survival and self sufficiency, including activities of daily living (ADL)-type activities such as hygiene and self care, walking inside, walking outside, and using transportation or driving; (2) *committed* activities, associated with one's principal productive social roles, such as paid work, household responsibilities, child and family care; and

(3) *discretionary* activities, such as socialising, exercise, engaging in leisure time activities and pastimes, participating in religious or spiritual activities, and pursuing volunteer work or hobbies, or other activities that individuals undertake for relaxation and pleasure.

Disability research has focused on basic activities of daily living (such as personal hygiene, transfers), independent activities of daily living (IADLs, such as preparing meals), and employment, corresponding to obligatory and some committed activities, and has thus ignored a great deal of daily life, particularly valued discretionary activities.<sup>3</sup> This emphasis reflects assumptions by researchers that ADLs, IADLs, and employment are a priori more important and that difficulty doing them is thus more significant. These assumptions may, in fact, not be true. Some activities are more important or more meaningful to individuals than others, and the person specific meaning, or “value,” attached to activities may affect the impact of disability. The importance of individual priorities and values, and the failure of common functional assessments to take these individual values into account, has been recognised by some researchers, and studies have shown that a large proportion of activities that individuals deem to be important are outside the realm of ADLs, IADLs, and employment.<sup>9–11</sup> Functioning in discretionary, valued life activities (VLAs) may also be more strongly linked to satisfaction with function and psychological wellbeing than more basic ADL-type levels of functioning.<sup>12–15</sup> At the same time, as individuals begin to have difficulty with or require more time to carry out basic activities, discretionary activities may be relinquished in

**Abbreviations:** HAQ, Health Assessment Questionnaire; VLA, valued life activity

order to accommodate the additional time and energy requirements needed for basic activities.<sup>16, 17</sup>

Functional limitations and disability resulting from rheumatoid arthritis have been extensively studied. The majority of disability research in rheumatoid arthritis has focused on ADLs, IADLs, and work and has presented a consistent picture of impaired functioning in these domains.<sup>18–24</sup> Some research has focused on disability in a broader range of life activities, and the impact of rheumatoid arthritis may be seen in such activities. In a variety of studies, individuals with rheumatoid arthritis have reported significant limitations in their ability to carry out general household cleaning activities, laundry, shopping or errands, cooking, and child and family care, and interference with performance of hobbies and pastimes and with sexual interest and activities.<sup>10, 22, 25–31</sup> However, none of these studies has undertaken an assessment of the prevalence of disability among individuals with rheumatoid arthritis in which a broad range of activities, spanning obligatory, committed, and discretionary activities, was included.

This paper presents data on disability in a wide range of life activities, and also identifies factors that are associated with such disability, using the Verbrugge and Jette model of disablement as a framework.

## METHODS

### Sample

The sample for the present study was drawn from the 2003 wave of the UCSF rheumatoid arthritis panel study (n = 548). The UCSF rheumatoid arthritis panel was constructed in 1982 from a random sample of rheumatologists practicing in Northern California. Participants have been recruited from lists maintained by participating rheumatologists of all persons with rheumatoid arthritis presenting to their offices over a one month period, and expressing an interest in participating in the study. The original rheumatoid arthritis panel consisted of 822 patients who were enrolled between June 1982 and July 1983. There were subsequently four additional enrolment periods in 1989–90, 1995, 1999, and 2003, during which 203, 131, 122, and 169 individuals were enrolled, respectively. Retention from year to year has

averaged 93%; the 7% attrition includes deaths. The principal data source for the rheumatoid arthritis panel is an annual telephone interview which includes questions on demographics, arthritis symptoms, co-morbidities, and functioning.

The study was approved by the UCSF Committee on Human Research.

### Variables

The VLA scale has its roots in a study by Yelin *et al* in which a measure of 75 life activities was developed based on time-budget survey research studies to determine the impact of arthritis.<sup>28</sup> Most of the activities assessed were things that one might do on an everyday or frequent basis, such as cooking, shopping for food, visiting with family, getting around the neighbourhood, and being involved with hobbies and crafts. When this list was incorporated into the rheumatoid arthritis panel interview, individuals were asked to rate how important it was to them to be able to undertake that activity, as well as whether they had participated in each activity in the past six months. Ten activities that were reported by fewer than 10% of the subjects were omitted (examples were doing major maintenance outside the house, such as roofing; going to bars and nightclubs). The activities were then grouped into 13 domains on a conceptual basis: home maintenance, housework, shopping and errands, nurturing activities, social communication and interaction, participation in social events, service activities, entertainment activities outside the home, sedentary leisure activities in the home, recreational activities, religious activities, transportation, and work. Domain categorisations were confirmed in two ways: with factor analyses of the importance ratings, and by examining the internal consistency (Cronbach's  $\alpha$ ) of each domain.<sup>25</sup>

Over the past decade, the VLA scale has been modified and refined. Respondents have been asked over multiple waves to identify activities or activity domains in addition to those queried that have been affected by their condition. Revisions have been made to the VLA scale based on those accumulated responses as well as analysis of previous versions of the scale. The version of the VLA scale used in these analyses includes 26 activity domains covering obligatory, committed, and

**Table 1** Valued life activity scale items

Subscale*	Item
O	1. Taking care of your basic needs, such as bathing, washing, getting dressed, or taking care of personal hygiene
C	2. Preparing meals and cooking
C	3. Light housework, such as dusting or laundry
C	4. Heavier housework, such as vacuuming, changing sheets, or cleaning floors
C	5. Other work around the house, such as making minor home repairs or working in the garage fixing things
D	6. Gardening or working in your yard
C	7. Shopping and doing errands
O	8. Going to appointments, such as going to the doctor or dentist, or going to have your hair cut/done
C	9. Taking care of your children/grandchildren or doing things for them
D	10. Participating in activities with your children/grandchildren
C	11. Taking care of other family members, such as your spouse or parent, or other people close to you
D	12. Visiting friends or family members in their home
D	13. Going to parties, celebrations, or other social events
D	14. Having friends and family members visit you in your home
O	15. Walking or getting around inside your home
O	16. Walking outside, just to get around, in the area around your home or other places you need to go on a regular basis (this does not include walking for exercise)
D	17. Participating in leisure activities in your home, such as reading, watching television, or listening to music
D	18. Participating in leisure activities outside your home, such as playing cards or bingo, or going to movies/restaurants
D	19. Working on hobbies or crafts or creative activities, such as sewing, woodwork, or painting
D	20. Participating in moderate physical recreational activities, such as dancing, playing golf, or bowling
D	21. Participating in vigorous physical recreational activities, such as walking for exercise, jogging, bicycling, swimming, or water aerobics
O	22. Getting around your community by car or public transportation
D	23. Travelling out of town
D	24. Participating in religious or spiritual activities
D	25. Doing volunteer work
C	26. Working at a job for pay

\* C, committed; D, discretionary, O, obligatory.

**Table 2** Subject characteristics

	Mean (SD)	n (%)
Age (years)	60.1 (13.2)	
Female		458 (83.6%)
Duration of RA	18.4 (11.9)	
Pain rating (0, no pain; 100, very severe pain)	30.1 (26.9)	
Severe or very severe fatigue		102 (18.7%)
Morning stiffness duration 1 hour or more		111 (20.3%)
Joint changes in hands		268 (49.0%)
Joint changes in feet		206 (37.6%)
Co-morbidities		
0		266 (48.5%)
1		198 (36.1%)
2 or more		84 (15.4%)
HAQ score	1.02 (0.73)	

HAQ, Health Assessment Questionnaire; RA, rheumatoid arthritis.

discretionary activities. The full text of the scale items is shown in table 1. Activities were defined as obligatory, committed, or discretionary based on the definitions of these activity categories by Verbrugge.<sup>3 7 8</sup>

Assessment of disability with the VLA scale represents advancement over previous instruments in two ways. First, a wide spectrum of activities is included, ranging from obligatory activities, such as self care, to discretionary activities, such as recreation and social participation. Second, the VLA scale takes personal value into account. Activities that are not applicable to an individual (for example, "taking care of children" if the individual has no children) or are not important to the individual (such as "cooking" if the spouse does all of the cooking) are not included in scoring of the scale. Finally, unlike most disability indices, the VLA scale asks respondents to attribute performance difficulties to the health condition under study.

In the telephone interview, participants rated the difficulty of performing the 26 life activities, using a 4 point scale corresponding to the response scale of the health assessment questionnaire (HAQ): 0, no difficulty to 3, unable to perform. Activities that participants deemed unimportant to them, or that they did not do for reasons unrelated to rheumatoid arthritis, were not rated and were not included in scoring.

Three types of VLA summary measure scores were calculated: the number of activities that individuals were completely unable to do because of rheumatoid arthritis (*unable*), the number of activities that were affected by rheumatoid arthritis (unable to do or any level of difficulty; *affected*), and the average difficulty score (*difficulty*). These scores were calculated for the total VLA scale, and for the obligatory, committed, and discretionary subscales.

### Predictors of VLA disability

Potential predictors of VLA disability were selected based on the Verbrugge and Jette model, and included measures of disease status and functional limitations. Measures of disease status, representing the "impairments" stage of the disablement model, included the following variables. Escalante and colleagues, in their test of the disablement model, also used these types of symptom measures to represent the impairment stage of the model.<sup>32</sup>

- Number of painful joints/joint groups, reported from a list of 17.
- Number of swollen joints/joint groups, reported from a list of 14.
- Rating of pain severity on the day of the interview, on a scale of 0 (no pain) to 100 (very severe pain).<sup>33</sup>

- Rating of fatigue in the past two weeks as none, very mild, mild, moderate, severe, or very severe. Ratings were grouped into two categories, none through moderate v severe or very severe.
- Duration of morning stiffness, dichotomised as less than one hour v one hour or more.
- Changes in the shape or appearance of hands or feet, assessed with the questions, "Has your rheumatoid arthritis [ever/in the past year] changed the shape or appearance of your [hands/feet]?" These questions were intended to assess joint deformities or structural derangements in the hands and feet, using lay terminology.

Functional limitations were assessed with the HAQ, a widely used measure of basic functioning specifically developed to measure functioning among persons with arthritis.<sup>33</sup> Although the HAQ is generally used as a measure of disability, the majority of the individual items actually reflect functional limitations as defined by the Nagi and Verbrugge models. HAQ scores range from 0 to 3, with higher scores indicating greater limitations.

### Analysis

Frequency distributions of difficulty ratings for each of the 26 VLAs were tabulated, and means and standard deviations of scale scores were calculated. The proportion of activities in each category that individuals reported affected (or unable) was calculated (for example, the number of obligatory activities affected/5 [the total number of obligatory activities assessed]). Factors associated with VLA disability were identified using multiple linear regression analyses, with VLA disability scores as dependent variables and measures of disease status and functional limitations as independent variables. The first set of regression analyses included the number of painful joints, the number of swollen joints, pain rating, fatigue rating, duration of morning stiffness, and joint changes in hands and feet, as well as age, sex, and duration of rheumatoid arthritis. The second set of analyses retained all of these variables and added the HAQ score.

## RESULTS

### Subject characteristics

The majority of subjects (83.6%) were female. Mean age was 60 years and mean duration of rheumatoid arthritis was 18 years. Additional characteristics may be seen in table 2.

### Difficulty ratings for valued life activities

Table 3 shows the means and frequencies of the difficulty ratings for individual activities. The activities most often affected by rheumatoid arthritis were in the committed and discretionary categories—Committed: heavy housework (85%), minor repairs (82%), and paid work (73%); Discretionary: gardening (87%), physical activities (moderate, 80%, and vigorous, 78%), and hobbies (75%). These activities also had the highest mean difficulty ratings. Substantial proportions of individuals were unable to undertake these activities. Obligatory activities had the lowest difficulty ratings, and there was little variability in ratings of specific activities. Both committed and discretionary activities showed a fairly wide range of proportions of individuals whose activities in that domain were affected and a wide range of mean difficulty ratings.

Almost half the sample (49%) was unable to do at least one VLA, the frequency being highest for discretionary activities (40%; table 4). The mean number of VLAs that participants were unable to undertake was 1.65, again with a preponderance among discretionary activities. Almost all participants (95%) reported at least one VLA affected by rheumatoid arthritis, with over half (68%) reporting an obligatory activity

**Table 3** Difficulty ratings for valued life activities: 2003 rheumatoid arthritis panel (n = 548)

	n*	Per cent affected	Mean difficulty rating (SD)	Difficulty rating (%)			
				None	A little	A lot	Unable
<i>Obligatory activities</i>							
Basic needs	548	41	0.44 (0.56)	59	38	3	0
Appointments	547	31	0.36 (0.58)	69	25	5	0
Walk inside	547	45	0.49 (0.59)	55	42	3	1
Walk outside	546	57	0.69 (0.69)	43	47	9	1
Car/transit	547	27	0.32 (0.58)	73	22	4	1
<i>Committed activities</i>							
Light housework	525	57	0.71 (0.75)	43	46	7	4
Meals/cook	520	59	0.72 (0.72)	41	50	6	3
Shopping/errands	542	57	0.73 (0.77)	43	45	8	4
Child care	272	60	0.79 (0.80)	40	46	10	5
Other family care	346	47	0.66 (0.85)	53	35	7	6
Heavy housework	512	85	1.33 (0.91)	15	52	18	15
Paid work	317	73	1.31 (1.14)	27	43	4	27
Minor repairs	356	82	1.43 (1.06)	18	46	10	25
<i>Discretionary activities</i>							
Leisure in home	547	16	0.17 (0.41)	84	15	1	0
Religious/spiritual activities	415	30	0.41 (0.73)	70	22	4	4
Having others visit	538	40	0.44 (0.57)	60	37	4	0
Visiting others	536	35	0.45 (0.70)	65	28	5	2
Leisure out of home	534	46	0.57 (0.73)	54	38	5	3
Parties/events	529	47	0.61 (0.78)	53	36	7	4
Travel	524	57	0.76 (0.80)	43	42	11	4
Activities with children	305	66	0.82 (0.74)	34	52	11	3
Volunteer work	356	59	1.05 (1.14)	41	33	6	21
Hobbies	435	75	1.10 (0.93)	25	53	9	13
Gardening	434	87	1.40 (0.92)	13	52	18	18
Moderate physical activities	459	80	1.41 (1.06)	20	41	15	23
Vigorous physical activities	504	78	1.43 (1.11)	22	40	11	27

\*Response frequencies vary as a function of the number of participants reporting that the activity either was not important to them or not applicable to them.

affected and over 90% reporting a committed or discretionary activity affected. The committed and discretionary frequencies were similar. The mean number of activities affected was 12. While the number of discretionary activities affected was greater than the number of committed activities affected, the proportion of activities affected in each domain was quite similar.

### Predictors of VLA disability

The disablement model would hypothesise that measures of disease status would predict functional limitations (in this case, HAQ), and that in turn functional limitations would herald disability. All disease measures were significant predictors of HAQ score and accounted for a substantial portion of the variance in HAQ (adjusted  $R^2 = 0.45$ ; data not

shown). In models including only symptom measures, age, sex, and duration of rheumatoid arthritis, the symptom measures were robust predictors of VLA disability, with model  $R^2$  values ranging from 0.28 (for *unable*) to 0.47 (for *difficulty*) for total VLA summary scores (table 5). Model  $R^2$  values were somewhat lower for the subscales (that is, obligatory, committed, and discretionary activities), but, with the exception of obligatory *unable*, all models were statistically significant and accounted for 22–45% of the variance in VLA disability. Adding HAQ to the regression models significantly increased the model  $R^2$  in all cases ( $p < 0.0001$ ), and changed the patterns of association. HAQ score appeared to mediate the effects of many of the disease measures, as would be predicted by the disablement model, and was a highly significant predictor of VLA disability scores in all cases.

**Table 4** Valued life activity summary scores

Disability scores	All activities (26 items)	Obligatory (5 items)	Committed (8 items)	Discretionary (13 items)
<i>Unable*</i>				
Unable to perform at least one VLA	49.1%	1.6%	31.3%	40.2%
Mean (SD) number of activities	1.65 (2.75)	0.03 (0.25)	0.63 (1.22)	0.99 (1.67)
Proportion of activities queried	6.3%	0.6%	7.9%	7.6%
<i>Affected†</i>				
At least one VLA affected	94.9%	68.4%	91.4%	92.5%
Mean (SD) number of activities	12.01 (7.40)	2.01 (1.87)	4.03 (2.38)	5.98 (3.77)
Proportion of activities queried	46.2%	40.1%	50.4%	46.0%
<i>Difficulty‡</i>				
	0.76 (0.57)	0.46 (0.49)	0.93 (0.71)	0.79 (0.60)

\*Unable to do.

†Affected by rheumatoid arthritis—that is, either difficulty or unable to do.

‡Mean (SD).

VLA, valued life activity.



**Table 5** Predictors of valued life activity disability

Variable	Demographic and symptom measures only				Adding HAQ to regression model			
	Total	Obligatory	Committed	Discretionary	Total	Obligatory	Committed	Discretionary
<b>Unable</b>								
Age	0.04§	0.0007	0.007	0.03§	0.01	−0.0005	−0.003	0.01†
Female	0.39	−0.03	0.22	0.20	−0.13	−0.05	0.005	−0.08
RA duration	0.04§	0.002*	0.01†	0.02‡	0.01	0.001	0.002	0.006
Pain rating	0.01*	−0.00004	0.002	0.008†	−0.003	−0.0006	−0.003	0.0007
No of painful joints	0.05	−0.00001	0.04*	0.009	−0.03	−0.004	0.007	−0.03
No of swollen joints	0.10*	0.009	0.03	0.06*	0.02	0.005	−0.001	0.01
Fatigue	1.26§	0.03	0.62§	0.62‡	0.724†	0.001	0.41‡	0.33*
AM stiffness	0.89§	0.001	0.35†	0.54†	0.64†	−0.01	0.25*	0.40†
Hands	0.26	−0.02	0.15	0.13	−0.02	−0.03	0.03	−0.02
Feet	0.47*	0.0	0.09	0.37†	−0.05	−0.02	−0.12	0.09
HAQ	—	—	—	—	2.44§	0.11§	0.99§	1.34§
Model R <sup>2</sup>	0.28	0.01	0.22	0.27	0.50	0.07	0.41	0.45
<b>Affected</b>								
Age	−0.01	0.02†	−0.02‡	0.0004	−0.07§	−0.0004	−0.04§	−0.03‡
Female	0.53	−0.05	0.51*	0.08	−0.83	−0.40†	0.11	−0.55
RA duration	0.07‡	0.01*	0.02†	0.04‡	0.005	−0.003	0.001	0.007
Pain rating	0.07§	0.02§	0.02§	0.04§	0.04‡	0.007†	0.008*	0.02§
No of painful joints	0.23†	0.07†	0.07*	0.10*	0.04	0.02	0.01	0.009
No of swollen joints	0.31†	0.08†	0.08*	0.16†	0.09	0.02	0.01	0.05
Fatigue	3.18§	0.74§	0.70†	1.75§	1.81†	0.39†	0.31	1.12‡
AM stiffness	1.27	0.31	0.36	0.60	0.62	0.14	0.17	0.30
Hands	0.90	0.18	0.26	0.46	0.16	−0.007	0.05	0.12
Feet	1.58†	0.44†	0.63†	0.50	0.21	0.10	0.24	−0.12
HAQ	—	—	—	—	6.40§	1.63§	1.85§	2.92§
Model R <sup>2</sup>	0.38	0.36	0.29	0.34	0.60	0.58	0.46	0.52
<b>Difficulty</b>								
Age	0.005‡	0.005‡	0.004*	0.006§	−0.0008	0.0003	−0.003*	0.0004
Female	0.06	−0.02	0.17†	0.03	−0.06	−0.12†	0.03	−0.09*
RA duration	0.007§	0.004†	0.008§	0.007§	0.0005	−0.0005	0.0007	0.0007
Pain rating	0.004§	0.02§	0.004§	0.005§	0.002†	0.001*	0.0008	0.002†
No of painful joints	0.02†	0.02†	0.02†	0.02	0.0005	0.004	0.002	−0.0007
No of swollen joints	0.03*	0.02†	0.03†	0.03	0.008	0.009	0.003	0.009
Fatigue	0.31§	0.22§	0.32§	0.34§	0.19§	0.13‡	0.17‡	0.22§
AM stiffness	0.19§	0.09*	0.25‡	0.20‡	0.13‡	0.05	0.18‡	0.14‡
Hands	0.06*	0.03	0.07	0.07	−0.005	−0.02	−0.01	0.004
Feet	0.14‡	0.12†	0.18‡	0.12†	0.02	0.02	0.03	0.009
HAQ	—	—	—	—	0.56§	0.44§	0.70§	0.54§
Model R <sup>2</sup>	0.43	0.37	0.40	0.42	0.75	0.61	0.69	0.69

Numerical values are the regression parameters (b) from multiple regression analyses. Symbols indicate significance level of variable in multiple regression models:

\*p<0.05; †p<0.01; ‡p<0.001; §p<0.0001.

The increase in R<sup>2</sup> for models when HAQ was entered was significant at p<0.0001 in all cases.

Commit, committed; Disc, discretionary; HAQ, health assessment questionnaire; Oblig, obligatory; RA, rheumatoid arthritis.

## DISCUSSION

VLA disability is common among individuals with rheumatoid arthritis. About half this sample was unable to undertake at least one VLA because of rheumatoid arthritis, and almost all reported at least one VLA affected by the disease. Obligatory activities were the least affected, regardless of how VLA disability was defined. There was little difference between committed and discretionary activities when VLA disability was defined as the number of activities affected. However, the likelihood of being unable to undertake at least one VLA increased from a very small percentage for obligatory activities, to about 30% for committed, to 40% for discretionary, suggesting that discretionary activities are the ones most commonly relinquished. Whether this is a voluntary relinquishment, to allow time or energy for other activities, or whether these activities are lost because of functional limitations and the increased physical demands of these activities requires further examination. The higher difficulty ratings seen for committed activities may be an indication that these activities, necessary for meeting life roles, require more effort and thus leave less time and effort for more discretionary activities. This hypothesis is consistent with previous reports that, when dealing with disability, people may give up some activities in order to have time and energy for others.<sup>16 17 28</sup>

The results of these analyses supported the Verbrugge and Jette disablement model, although the test of the model was limited by the lack of variables representing the "pathology" stage, such as laboratory measures of inflammation. Symptom measures, representing "impairments," were associated with functional limitations (HAQ score). Various studies have demonstrated the relation between symptom measures ("impairments") and HAQ score.<sup>34 35</sup> Most research has treated the HAQ score as a measure of disability, but in the context of the disablement model all the HAQ items except two (the "other activities" subscale) correspond to functional limitations, such as difficulty in reaching, gripping, and arising. Previous work supports differentiation of the HAQ from measures of disability. For example, the overlap between decline in functioning measured by the HAQ and decline in functioning measured by a VLA-type measure is minimal. In one study of 47 women who experienced a decline according to one of the measures, only six (13%) experienced a decline according to both measures.<sup>12</sup> Previous studies have also used HAQ as a predictor of disability, particularly work disability,<sup>19–24 36 37</sup> implicitly suggesting that what the HAQ measures is a precursor to disability.

As noted above, symptom measures were associated with functional limitations (HAQ). Functional limitations were, in turn, associated with VLA disability and mediated much of

the relation between symptoms and disability. Some symptom measures appeared to have direct associations with VLA disability in addition to the mediated associations. Fatigue and pain, in particular, had independent associations with VLA disability, even when taking HAQ into account, suggesting that these impairments (or symptoms) are more closely tied to disability than demographic characteristics and other symptoms. HAQ was by far the strongest predictor of VLA disability, regardless of how VLA disability was defined.

Use of three measures of VLA disability leads to the question of which measure is "best." Previous research has focused on the loss of activities, or the equivalent of the number of activities individuals are unable to carry out, and has shown robust associations with development of depression.<sup>12-13</sup> However, the proportion of variation in the number of relinquished activities that was explained by symptoms and functional limitations was considerably lower than the variation in the number of activities that were affected or carried out with difficulty, suggesting that inability to undertake activities may be influenced by additional unmeasured factors. Further study is needed to determine which VLA specifications are best suited to which situations. For example, to predict long term psychological outcomes, the "unable to perform" specification may be more sensitive, whereas to predict other outcomes another specification may be a better choice.

Why is it important to consider disability in valued life activities? The impact of disability is likely to vary according to the value that individuals place on affected activities. Performance of VLAs appears to be linked to psychological wellbeing more strongly than limitations in general function. Persons with rheumatoid arthritis who report high levels of depressive symptoms were involved in fewer VLAs than those who did not report depressive symptoms, and the loss of VLAs has been shown to be a stronger predictor of the subsequent onset of new depressive symptoms than a decline in function as measured by the HAQ.<sup>12-25</sup> Disability in certain types of activity, specifically in recreational and social activities, appears to be especially linked to the onset of depressive symptoms.<sup>13</sup> Several other researchers have addressed the issue of personal value by constructing "patient specific" measures.<sup>9-38-39</sup> Although these measures appear to be useful for monitoring individuals, difficulties have been reported when using them in aggregate situations.<sup>10-40</sup> Another consideration is that as more effective treatments become available, patient goals will likely expand beyond simple preservation of ADLs. Measurement of a wider range of life activities coincides with these new expectations.

There are potential limitations to this study. It is possible that our assessment of VLAs was incomplete. In fact, as a result of open ended queries about other activities that have been affected by rheumatoid arthritis, a new version of the VLA assessment is being developed and tested, to which additional life activities—such as sleep and intimate relations with partners—have been added. While this new measure may be more sensitive, there is no reason to believe that the overall tenor of these findings would change as a result. It is also possible that factors other than those included here may affect the association of VLA disability with general health status assessments. For example, obesity may affect both functional limitations and disability. Unfortunately, a measure of body composition was not available for this cohort, although such data will be collected in the future, enabling examination of this association at that time. The rheumatoid arthritis panel cohort may be unrepresentative of individuals with rheumatoid arthritis in some way; however, the cohort is very similar in measured characteristics to other large cohorts.<sup>41</sup> Nevertheless, because participants were recruited from community rheumatologists rather than through an

academic medical centre or tertiary care centre, it is probable that the distribution of disease severity and other relevant characteristics is more similar to the population of individuals with rheumatoid arthritis. Nonetheless, it is possible that individuals who visit rheumatologists for care are systematically different from those who do not; in particular, they may have more severe disease and more disability.

## Conclusions

Disability in valued life activities is very common among individuals with rheumatoid arthritis. Such disability appears to play a substantial role in the patient's psychological status, as demonstrated in previous studies.<sup>12-13</sup> Future research topics should include identification of factors associated with the development and progress of VLA disability, as well as factors that may protect against or ameliorate such disability. The latter are especially important, as these may represent targets for potential intervention.

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